

Assessment of the Family Caregiver Needs for Patient with Cancer regarding Palliative Care
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Abstract

Background: Cancer is one of the leading causes of death globally and palliative care is an integral component of the comprehensive care for patients in oncology. It is improving the quality of life. **The aim of the study:** was to assess the family caregivers' needs of patient with cancer regarding palliative care. **Subjects and Method: Design:** Descriptive study design was utilized in this study. **Setting:** This study was conducted in Oncology Outpatient Clinic of Tanta Health Insurance Hospital at Tanta city. **Subjects:** Simple randomized sampling of 400 family caregiver of patient with cancer who attended the previous setting. **Tool of the study:** Structured interviews schedule was used to collect the necessary data it composed of three parts. **Part 1:** Socio-demographic characteristics of the family caregivers. Socio-demographic characteristics and medical history of cancer patient. **Part 2:** Needs of the family caregivers about the palliative care and consisted of five types of needs (Informational, financial, Physical, Psychological and Social) **Result:** 46.8 % of the family caregivers had high need level for information, while 47% of them had high financial need level for palliative care and 44 % of them had low physical needs level. Moreover 58.3% of them had high psychological needs, and (70 %) of them had high social needs level about palliative care. **Conclusion and Recommendations:** Most of the family caregivers had high and moderate total needs level about palliative care: Therefore, community health nurse should provide special educational programs to all family caregivers to upgrade their knowledge about palliative care.

Keyword: Needs, Family caregiver, Cancer patient, Palliative care

Introduction

Cancer is one of the major health problems. Globally the number of new cases is expected to rise by about 70% over the next two decades. It is the leading cause of morbidity and mortality in all age groups⁽¹⁾. In 2018, an estimated 18.1 million new cases cancer was diagnosed globally, and 9.6 million died from the disease. One in five men and one in six women worldwide will develop cancer

during their lifetime, and one in eight men and one in eleven women will die from cancer. Worldwide cancer incidence and mortality are rapidly growing⁽²⁾. In Egypt, 2013 the result of the National population – Based cancer showed that the crude incidence rates on the national level for all sites excluding nonmelanoma skin cancer were 113.1/100,000 (both sexes), 115.7/100,000 (males), and 110.3/100,000 (females)⁽³⁾.

There are millions of cancer patients in need of palliative care. With careful planning of cancer palliative care within a comprehensive cancer control plan, a large proportion of advanced cancer patient could be relieved from their suffering and the quality of their lives could be improved. Significantly palliative care requires a strong network of trained health-care practitioners, community leaders, traditional healers, and family caregivers with specific roles and functions across the different levels of care and within the community⁽⁴⁾.

Palliative care (PC) is defined by the World Health Organization (WHO) as “an approach that improves the quality of life (QoL) of the patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems⁽⁵⁾”.

Palliative care can be provided across multiple settings including in hospitals, at home, as part of community palliative care programs, and in skilled nursing facilities. Interdisciplinary palliative care teams work with people and their families to clarify goals of care and provide symptom management, psycho-social, and spiritual support^(6,7).

Palliative care is treatment to relieve symptoms caused by cancer, rather than cure, and improve the quality of patient's life and their families. Palliative care can help people live more comfortably^(8,9). Additionally, it is an urgent humanitarian need worldwide for people with cancer and other chronic fatal diseases and particularly needed in places with a high proportion of

patients in advanced stages of cancer where there is little chance of cure. Also, it is necessary to relief from physical, psychosocial, and spiritual problems. Furthermore, it is most effective when considered early in the course of the illness. Early palliative care not only improves the quality of life for patients but also reduces unnecessary hospitalizations and use of health-care services^(10,11).

Caregiving is most commonly used to address impairments related to old age, disability, a disease, or a mental disorder. Family members have provided care and support to each other during times of illness. In most cases the situation makes a family member a “family caregiver” that defined as any person who, without being a professional or belonging to a social support network, usually lives with the patient and by any way is directly implicated in the patient's care or is directly affected by the patient's health problem. Typical duties of a family caregiver might include taking care of someone who has a chronic illness our disease; managing medications or talking to doctors and nurses on someone's behalf; helping to bath or dress someone who is frail or disabled or taking care of household chores, meals, or bills for someone who cannot do these things alone. With an increasingly aging population in all developed societies, the role of caregiver has been increasingly recognized as an important one, both functionally and economically. Many organizations which provide support for persons with disabilities have developed various forms of support for caregiver as well emotional support to terminally ill patients and their families⁽¹²⁾.

Nurses play an important role to provide information toward family caregiver in a clear, understandable way through verbal, written, and electronic methods. Caregivers want concrete information about medications, tests, treatments, and resources. They also want time to have their questions answered and can provide anticipatory guidance for what the caregiver can expect. This kind of information can relieve caregivers' distress arising from uncertainties about their ill family members' disease and treatment status and the care they may need⁽¹³⁾.

Significant of the study

Several studies have shown that early involvement of specialized palliative care services for patients with advanced cancer improves quality of life, increases satisfaction with care and mitigates depression⁽⁶⁻⁸⁾. So, studying the needs of family Caregiver of Patient with Cancer regarding Palliative Care is an important.

Subjects and Method

Aim of the Study:

Assess family caregivers' needs of patient with cancer regarding palliative care.

Research question:

What are the needs of the family caregivers of patient with cancer regarding palliative care?

Study design:

The descriptive study design was utilized in this study.

Study setting:

This study was conducted in Oncology Outpatient Clinic of Tanta Health Insurance Hospital affiliated to Health Insurance Organization, Tanta city, Al Gharbia Governorate.

Study Subjects:

Simple randomized sampling of 400 family caregiver of patient with cancer who attended the previous setting. The sample size was calculated using Epi- Info software statistical package. Confidence limit is 95% and error of 5% The sample size was calculated as $N > 384$. The sample size increased to 400 to increase the validity of the result.

Inclusion criteria of family caregivers

Principal adult family caregiver of cancer patient.

Tool of the study:

A structured interview schedule was developed and used by the researcher in order to obtain the necessary data for this study. It consisted of the following parts:

Part (1): Socio-demographic characteristics of the family caregivers,

this part contained of 14 questions included: age, sex, educational level, marital status, residence, degree of kinship, monthly income, job, previous death experience and current experience in the care of cancer patient, how many people live in the caregivers' household, the patient live in the same household, and duration of caregiving role.

Part (2): Socio-demographic characteristics and medical history of cancer patient,

this part included of 12 questions included: age, sex, education, occupation, income, marital status, number of children, protocol of treatment, duration of cancer, and its type.

Part (3): Needs of the family caregivers about the palliative care.

It was developed by the researcher based on the literature review⁽¹²⁻¹⁵⁾ to assess the family caregivers needs it consisted of five sections.

Section (A): Informational needs, this section included the following:

1-General informational needs about palliative care. This section consisted of 8 questions used to assess the family caregivers' information regarding the palliative care of patient with cancer which contain the following: the awareness of palliative care, principles, aim, services provided, the team of palliative care, for whom palliative care should be provided, and setting that provide palliative care.

2-Specific informational needs: This section was developed by Family Caregiver Alliance (2006)⁽¹⁴⁾, it composed of (12) items that cover the needs for information about disease stage, care to the patient, dietary information, cancer-specific information, homecare information, psychological support information, health information, insurance, and social welfare information.

Section (B): Financial needs, this section consisted of five questions included the need for cost of traveling to and from medical appointment, drug cost and investigation, preparing for surgery, missing work, food supply and cost of uncovered services with insurance.

Section (C): Physical needs, this section consisted of twelve questions included the need for: assistance in moving, lifting, bathing, massaging, operating medical equipment, healthy food cooking, get enough time to sleep, health promotion, follow up to control their own disease, and examine current health patterns and weight changes.

Section (D): Psychological needs, this section consisted of eleven questions included the need for psychological support from family member, group

discussion to express emotion and reduce anxiety and time to breath⁽¹⁵⁾.

section (E): Social needs, this section consisted of eight questions included the need for: social support from the family members and friends and health care professional, guidance from health care providers, time to attend social event like party or condolences, time for well-being and not allowed to be social isolated, social network to provide support.

Scoring system of caregiver needs:

The total scores of caregivers' need was classified as follow:

- Low need level <50% of the total needs score
- Moderate need level \geq 50%-70% of the total needs score
- High need level >70% of the total needs score

The operation of this study was carried out as follows:

1-Obtaining approvals:

-An official permission to conduct the study were obtained from the Dean of Faculty of Nursing to Director of Health Insurance Organization in Tanta City, Al-Gharbiya Governorate.

-The director of the outpatient department of Health Insurance was informed about the study objectives to take their permission to collect data from the selected settings.

2- Ethical and legal considerations:

- Ethical and legal considerations was considered all over the study phases as the following:
- The approval of the ethical committee of the faculty was obtained.
- An informed consent was obtained from study subjects after providing appropriate

explanation about the purpose of the study.

- Every family caregiver was informed about the purpose and the benefits of the study at the beginning of interview.
- Nature of the study were not cause any harm or pain for the entire sample.
- Privacy and confidentiality were put into consideration regarding the data collected.

3-Developing the tools:

- The study tool was developed and translated into Arabic language by the researcher based on literature review, and modified to suit the level of understanding of all subjects.
- The study tool was tested for its content validity by a jury of five professors in Community Health Nursing at Faculty of Nursing in Tanta University and Public Health Medicine before conducting the study.

4-The pilot study:

A pilot study was carried out on 10% of family caregivers and was not included in the study sample.

- Reliability of the study tool was done using Cronbach Alpha test and it was (0.876) which indicate highly reliable tool.

5-The actual study:

- The family caregivers of cancer patients were interviewed at Oncology Outpatient Clinic of Tanta Health Insurance by the researcher using the previous tools to collect the necessary data.
- Collection of data was continued during a period about six months, starting at December 2020 and ending in May 2021. The time needed for each interview to complete the data collection sheet ranged from 20-30 minutes.

6-Statistical analysis:

All statistical analyses were performed using SPSS for windows version 20.0 (SPSS, Chicago, IL). All continuous data were normally distributed and were expressed in mean \pm standard deviation (SD). Categorical data were expressed in number and percentage. Chi-square test was used for comparison of variables with categorical data. Correlation co-efficient test was used to test for correlations between two variables with continuous data. Statistical significance was set at $p < 0.05$.

Results

Table I: Shows distribution of studied family caregivers according to their socio-demographic characteristics. Regarding the studied family caregivers age more than one third of them (34.5 %) their ranged from age 31 to less than 41 years and only 17 % aged more than 50 years. Concerning sex of the studied family caregivers', 61.3 % of them were females, whereas more than two thirds (69.8%) of them were married. As regards to studied family caregivers' education the table illustrates that, more than half (52.5%) of studied family caregivers had university /post graduate education, furthermore 59 % of them lived in rural areas. Concerning degree of a kinship, 52.5% studied family caregivers had first degree of kinship. Regarding the studied family caregivers' occupation, the table illustrates that, 39% of the studied family caregivers worked as government employees, furthermore 70.8% of them lived with the patients in the same house

Table II: The table illustrates that, about one half (46.8 %) of the studied family caregivers had high informational need

level regarding palliative care with Mean \pm SD 7.4 \pm 2.9, while 47 % of them had high financial need level regarding palliative care with Mean \pm SD 3.1 \pm 1.4. Furthermore, 13.3 % of them had high physical needs level regarding palliative care with Mean \pm SD 9.1 \pm 3.6, in addition, more than half (58.3 %) of them had high psychological needs level regarding palliative care with Mean \pm SD 7.3 \pm 2.8 also, more than three quarters (79 %) of them had high social needs level regarding palliative care with Mean \pm SD 6.4 \pm 2.0.

Table III: Shows relation between the socio-demographic characteristics of the family caregivers and total needs score. The table shows that, there was a statistically significant relation between the studied family caregivers and total needs score about palliative care and all variables of their socio-demographic characteristics

except, residence marital status, occupation and presence of caregiver with the patient in the same house ($p < 0.05$).

Table IV: Shows correlation among total knowledge score and needs domains' scores and total needs score about palliative care of the family caregivers. The table presents that, there was a positive correlation between all domains of palliative needs among the family caregivers (informational needs score, financial needs score, physical needs score, psychological needs score and social needs score) and the total needs score ($p < 0.05$).

Figure 1: The figure illustrates that, 13.3 % of the studied family caregivers had good general knowledge about palliative care, while 46 % of them had fair general knowledge about palliative care, and 40.8 % of them had poor general knowledge about palliative care.

Table I: Distribution of studied family caregivers according to their socio-demographic characteristics

Socio-demographic characteristics of family caregivers	Studied family caregivers (n=400)	
	No	%
Age (years)		
- 21-	87	21.8
- 31 -	138	34.5
- 41 -	107	26.8
- > 50	68	17.0
- Mean ± SD		38.3±11.1
Sex		
- Male	155	38.8
- Female	245	61.3
Marital status		
- Married	279	69.8
- Widower	22	5.5
- Divorced	8	2.0
- Single	91	22.8
Education		
- Illiterate	279	69.8
- Elementary education	22	5.5
- Secondary/technical education	8	2.0
- University /post graduate education	91	22.8
Residence		
- Urban	164	41.0
- Rural	236	59.0
Degree of a kinship		
- First Degree	210	52.5
- Second Degree	110	27.5
- Husband/ wife	80	20.0
Occupation		
- Professional technicians	36	9.0
- craft work	20	5.0
- Self employed	51	12.8
- Government employee	156	39.0
- Un employed	137	34.3
Living with the patient in the same house		
- No	117	29.3
- Yes	283	70.7
Duration of caring for the patient (in Years)		
- < 3 Years	235	58.8
- 3 - 7 Years	143	35.8
- > 7 Years	22	5.5

Table II: Shows distribution of the studied family caregivers according to the total score of their total needs about palliative care.

Total needs about palliative care	Needs Level						Mean ±SD
	Low		Moderate		High		
	N	%	N	%	N	%	
Informational needs	110	27.5	103	25.8	187	46.8	7.4 ±2.9
Financial needs	67	16.8	145	36.3	188	47	3.1 ±1.4
Physical needs	176	44	171	42.8	53	13.3	9.1 ±3.6
Psychological needs	106	26.5	61	16.3	233	58.3	7.3 ±2.8
Social Needs	41	10.3	43	10.8	316	79.0	6.4 ±2.0

Table III: Relation between the socio-demographic characteristics of the family caregivers and total needs score

Socio-demographic characteristics of the family caregivers	Total needs score of studied family caregivers (N=400)							X ²	P
	Poor (n = 100)		Fair (n = 184)		Good (n = 116)				
	No	%	No	%	No	%			
Age (years)									
- 21-	13	13.0	41	22.3	33	28.4			
- 31-	35	35.0	65	35.3	38	32.8			
- 41-	24	24.0	41	22.3	42	36.2			
- > 50	28	28.0	37	20.1	3	2.6	33.956	<0.001*	
Sex									
- Male	60	60.0	69	37.5	26	22.4			
- Female	40	40.0	115	62.5	90	77.6	32.190	<0.001*	
Marital status									
- Married	72	72.0	127	69.0	80	69.0			
- Widower	8	8.0	8	4.3	6	5.2			
- Divorced	0	0.0	8	4.3	0	0.0			
- Single	20	20.0	41	22.3	30	25.9	11.935	0.063	
Education									
- Illiterate	4	4.0	10	5.4	14	12.1			
- Elementary education	11	11.0	12	6.5	4	15.5	9.975	0.041*	
- Secondary/technical education	37	37.0	72	39.1	26	22.4			
- University /post graduate education	48	48.0	90	48.9	72	62.1			
Residence									
- Urban	36	36.0	87	47.3	41	35.3			
- Rural	64	64.0	97	52.7	75	64.7	5.569	0.062	
Degree of a kinship									
- First degree	53	53.0	84	45.7	73	62.9			
- Second degree	23	23.0	62	33.7	25	21.6			
- Husband/ wife	24	24.0	38	20.7	18	15.5	10.854	0.028*	
Occupation									
Professional technicians	4	4.0	19	10.3	13	11.2			
Craft work	8	8.0	8	4.3	4	3.4			
Self-employed	12	12.0	27	14.7	12	10.3			
Government employee	48	48.0	68	37.0	40	34.5			
Un employed	28	28.0	62	33.7	47	40.5	12.753	0.121	
Presence of caregiver with the patient in the same house									
No	28	28.0	54	29.3	35	30.2			
Yes	72	72.0	130	70.7	81	69.8	0.124	0.940	
Duration of caring for the patient (In years)									
< 3 years	68	68.0	106	57.6	61	52.6			
3 - 7 years	28	28.0	60	32.6	55	47.4			
> 7 years	4	4.0	18	9.8	0	0.0	21.774	<0.001*	

*Significant (p<0.05)

Table IV: Correlation among total knowledge score and needs domains' scores and total needs score about palliative care of the family caregivers

	Informational needs Score	Financial needs Score	Physical needs Score	Psychological needs Score	Social needs Score	Total Needs Score
	R P	R P	R P	R P	r P	R P
Knowledge needs Score	0.085	-0.023	-0.043	0.311	0.237	0.157
	0.090	0.650	0.389	<0.001*	<0.001*	0.002*
	-----	0.318	0.199	0.465	0.567	0.732
Informational needs score	-----	<0.001*	<0.001*	<0.001*	<0.001*	<0.001*
	-----	-----	0.242	0.183	0.265	0.482
Finance needs score	-----	-----	<0.001*	<0.001*	<0.001*	<0.001*
Physical needs score	-----	-----	-----	0.356	0.212	0.662
	-----	-----	-----	<0.001*	<0.001*	<0.001*
Psychological needs score	-----	-----	-----	-----	0.695	0.793
	-----	-----	-----	-----	<0.001*	<0.001*
Social needs score	-----	-----	-----	-----	-----	0.755
	-----	-----	-----	-----	-----	<0.001*

*Significant (p<0.05)

Figure 1: Shows distribution of the studied family caregivers according to their total general knowledge about palliative care

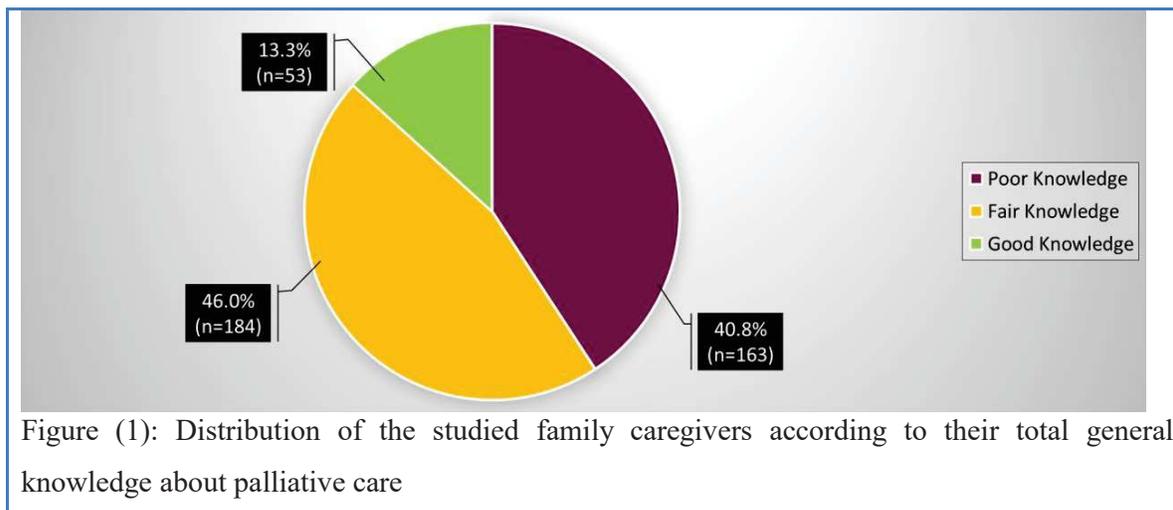


Figure (1): Distribution of the studied family caregivers according to their total general knowledge about palliative care

Discussion

Family caregivers provide substantial care for patients with advanced cancer, while suffering from hidden morbidity and unmet needs. Caregivers are partners, relatives, or friends who provide care that requires substantial time over months to years and involves performing a wide range of physically, socially, emotionally, or financially demanding tasks. Caregiving tasks are increasingly complex, particularly in advanced disease settings, and include assistance with activities of daily living, coordinating and attending hospital appointments, managing and providing medical care at home, and assisting with decision making and palliative care, which emphasizes family-centered care and improvement of outcomes for caregivers as well as patients. A family-centered palliative care approach within oncology, may lead to improved support for caregivers of patients with advanced cancer⁽¹⁶⁾.

As regarding the age, the results of the current study revealed that more than one third of the studied family caregivers aged between 31 to less than 40 years old with Mean \pm SD 38.3 \pm 11.1 years (Table I). These findings do not agree with the study done by **Akyar et al. (2019)**⁽¹⁷⁾, on 25 primary family caregivers of older individuals with cancer in Turkey about needs assessment for Turkish family caregivers of older persons with cancer: first-phase results of adapting an early palliative care model and founded that about one half of the studied family caregivers aged between 41 to less than 50 years old with Mean \pm SD 47.04 \pm 11.00 years. Age difference between studied

family caregivers may be due to setting difference and cultural, norms and economical characteristic between participants in the two settings.

As regards to number and distribution of the studied family caregivers according to the total score of their total needs about palliative care the results of the current study show that less than one third of the studied family caregivers had high total needs level about palliative care, about one quarter of them had low total needs level about palliative care, while less than one half of them had moderate total needs level about palliative care (**Table II**). This findings may be due to presence of more than one family care giver .These findings not matched with the study done by **Rezende et al. (2017)**⁽¹⁸⁾, on 100 participants in Brazil about burden on family caregivers of the elderly in oncologic palliative care and revealed that more than one half of the studied family caregivers had high total needs level about palliative care, about one quarter of them had moderate total needs level about palliative care , while minority of them had low total needs level about palliative care. These findings may be due to differences between the participants of the two studies regarding all the patient's and their caregivers needs, requirements to teach, counsel and support the individual and family through the continuum of care

Regarding the relationship between the studied caregiver's total needs score about palliative care and their socio-demographic characteristics the results of the current study revealed that there was a highly statistically significant relation was found between caregiver's total needs score and their age P=0.001 (**Table III**). These

findings completely go on the same line with the study done by **Shaffer et al. (2017)**⁽¹⁹⁾, on 275 participants in Boston, USA about mental and physical health correlates among family caregivers of patients with newly-diagnosed incurable cancer and revealed that there were a highly statistical significant relation was found between caregivers' needs (physical, mental) score and age $P=0.001$. These findings may be supported by the fact that with increase age increase all the needs of the palliative care patients and their caregivers that require continuous help and assistance especially physical and psychological needs.

Regarding the relationship between the studied caregivers' total needs score about palliative care and their socio-demographic characteristics the results of the current study present that there was a highly statistically significant relation was found between caregivers' total needs score and sex $P=0.001$ (**Table III**). These findings inconsistent with the findings of a study done by **Nipp et al. (2016)**⁽²⁰⁾, on 275 caregivers in Boston, USA about factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer and revealed that there was no a statistically significant relation was found between caregivers' total needs score and sex. These findings are a realistic result in accordance to the Egyptians population as males are different from females in their needs and requirements in caring and about how to fulfil these needs and may be due to different environment, different cultures and differences in educational level between the two studies.

Also, the results of the current study show that a highly statistically significant relation was found between social needs score and psychological needs score about palliative care ($P=0.001$) (**Table IV**). These findings matched with the findings of a study done by **Perpiñá-Galvañ et al. (2019)**⁽²¹⁾, on 77 caregivers in Spain about level of burden and health-related quality of life in caregivers of palliative care patients and found that there was a statistically significant relation was found between social needs score and psychological needs score. These similarities in findings may be due to in nature of connection between social and psychological needs as each one related to the other one and also due to similarities in demographic characteristics between the two studies. The results of the current study were able identified the needs of the family caregivers of patient with cancer regarding palliative care and these needs were general knowledge needs, informational needs, financial need, physical needs, psychological needs, social needs. So, this study was able to answer the proposed research question.

Conclusion

Based on the findings of the current study, it can be concluded that, less than one-third of the studied family caregivers had high total needs level about palliative care, while one quarter of them had low total needs level about palliative care, and about half of them had moderate total needs level about palliative care. There was a positive correlation between all domain of palliative needs among the family caregivers (informational needs score, financial needs score, physical needs score,

psychological needs score and social needs score) and the total needs score.

Recommendation

1. Community health nurse should provide special educational programs to all family caregivers to upgrade their knowledge about palliative care.
2. Instructional guidelines should be applied on a wide range through different places that serve the cancer patient.
3. Community support either governmental or non- governmental should be provided to family caregivers in order to meet their needs.
4. Further researches are required to investigate needs of family caregivers as informational needs, financial needs, physical needs, psychological needs and social needs.

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